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ABSTRACT

This annotated bibliography addresses issues, principles, programs, and research about respite care published in articles and books from 1978-1988. It covers a wide range of topics, from comprehensive overviews of respite issues, services, and policies to descriptions of specific respite care program models. A number of the bibliographic entries offer discussions of the benefits of respite care, and present the findings from studies designed to assess the impact of respite care on the lives of families. Policy issues, including funding questions, are examined, along with training issues, such as the need for training, necessary knowledge and skills for respite care providers, and an evaluation of training approaches. The 42 bibliography entries are presented in alphabetical order by author. Each annotation contains a summary of the main points or findings in considerable detail. The document concludes with a list of 43 respite care programs across the United States. (JDD)

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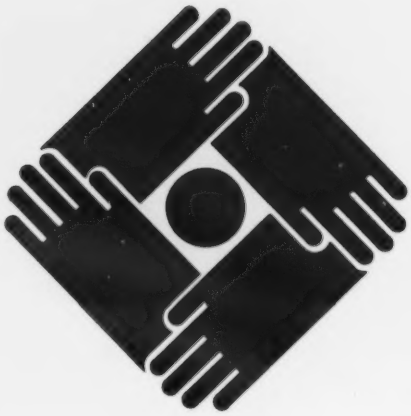

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RESPITE CARE:

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INTRODUCTION

This respite care bibliography was developed as part of a larger process undertaken to learn more about services that may be supportive to families who have children with serious emotional disabilities. Respite care is one of a set of support services that are increasingly recognized as necessary resources in helping families manage the complex tasks associated with meeting the needs of their special children. This bibliography is designed as a companion to a monograph on respite care also prepared through the Families as Allies Project of the Portland Research and Training Center.

The literature search uncovered very little written about respite programs specifically designed for children and adolescents with serious emotional problems. Much of the literature addressing issues, principles, programs, and research about respite care developed for other populations, however, appears to be relevant to families of children with emotional disabilities, and is included here.

The literature selected for this bibliography covers a wide range of topics, from comprehensive overviews of respite issues, services and policies (e.g., Cohen & Warren, 1985; Grayson, 1987; Salisbury & Intagliata, 1986) to descriptions of specific respite care program models (Ferguson, et al., 1983; Franz, 1980; Humphry and Labarrerre 1979; Joyce and Singer 1983; Milne, 1986). A number of authors discuss the benefits of respite care, and present the findings from studies designed to assess the impact of respite care on the lives of families (e.g., Halpern, 1985; Intagliata, 1986; Joyce and Singer, 1983; Powell and Ogle, 1986; Ptacek, et al., 1982; Upshur, 1982; and Wikler, et al., 1986). Policy issues, including funding questions are also addressed (see, e.g., Bamford, 1986; Castellani, 1986; Cohen, 1982; Joyce and Singer, 1983; Slater, 1986; Warren & Cohen, 1985; and Wilson, 1986; among others). Training issues, such as the need for training, necessary knowledge and skills for respite care providers, and an evaluation of training approaches are also the subject of a number of authors, including Chock and Glahn (1984), Neef, et al., (1986), Parrish, et al., (1986) and Shettle, et al, (1982).

The information-gathering process about respite care also involved telephone interviews with personnel from respite care programs around the country. We have also included the names, addresses and telephone numbers of these respite programs, and the name of a contact person, where available, so that readers interested in gathering more information about specific programs may do so.

The bibliography entries are presented in alphabetical order by author. Each annotation contains a summary of the main points or findings of the article or book. Considerable detail about the contents of articles is provided, on the assumption that many persons interested in learning more about respite care--parents, service providers, administrators and policy-makers--may not have easy access to the original works, or may not have the resources to undertake a comprehensive literature search and review.

We hope readers will find this bibliography useful, and we welcome comments and suggestions from those who use our materials. Please assist us in assessing the usefulness of this product by completing the evaluation form in the back of the bibliography, and returning it to us at the address given on the back of the form. An order form that may be used to order additional copies of this bibliography as well as other Research and Training Center products is also included at the end of this booklet.

B.J.F.

Arkava, M.L. and Mueller, D. (1978). Components of foster care for handicapped children. *Child Welfare*, 57(6), 339-345.

Key words: support services, foster families

The authors describe a study of the specific tasks and demands of foster care for children with handicaps. The foster parents' need for respite care services is said to result from these factors: (1) the long-term commitment necessary for the care of a child with handicaps; (2) the physical and emotional demands of providing routine, repetitive care for a child with special needs; (3) the restrictions on mobility for foster parents; and (4) the difficulties of finding appropriate baby-sitters and escaping routine tasks. Although this article calls for respite and other support services for foster parents, the needs and issues it describes are also felt by natural parents of children with handicaps.

Bamford, T.F. (1986). Unresolved Issues: A United Kingdom Respective. *British Journal of Social Work*, 16(supplement), 169-172.

Key word: policy

This article was written following an international conference on the integration of informal helping networks into social work practice. Although not specifically addressing respite services, the article is pertinent because of the relationship of informal support systems to respite care issues. This relationship is significant for at least three reasons: (1) respite care is often provided to a family informally by friends or relatives; (2) studies have frequently shown that families prefer to use already familiar family and social supports for respite; and (3) in determining program and policy, respite agencies face the choice of whether (or to what degree) family and community resources will be integrated into formal services. (See Wilson). Bamford states that informal helping networks present both risks and opportunities to social services. Fiscally conservative governments, he says, call for a "return to Victorian values with an emphasis on thrift and self-reliance", which "sometimes appears to imply that informal care is substitutable for public services." (p. 170). Rather than replacing each other, the author suggests that these two supports should be seen as complementary. Changes in family structure, social mobility and the roles of women as traditional caregivers are described as having had profound influence on informal helping networks. The author points out that frequently the burden of caring for individuals with handicaps is carried alone by families. He maintains that financial support from public agencies, accessible day care, social work help in constituting a network, and respite care provided by social services are all needed if the burden felt by caregivers is to be lessened. Issues posed by a greater emphasis on informal helping networks such as ethics,

confidentiality, and managerial control are also discussed. The author points out that informal helpers will create their own pressures for resources and assistance, and will not fit in well with the usual social service organizational structures

Borfitz-Mescon, J. (1988). Parent Written Care Plans: Instructions for the Respite Setting. *Exceptional Parent*, 18(3), 20-25.

Key words: parent input, stress

The author, a parent and nurse practitioner, describes the parent written care plan she developed for use by a nursing home staff after she decided to leave her special needs child in a nursing home for extended respite. A care plan can help alleviate parental concerns and anxiety as well as ensure that each caregiver knows as much as possible about the child. Further, care plans may be easily updated (particularly if a word processor is used) to reflect changes in the child's condition. The topics addressed may include: playing, communication, dehydration, fluids, sleeping, wheezing, feeding, comforting, medication and constipation. The author poses questions designed to assist parents in writing their own plans and includes sample portions of her child's care plan.

Castellani, J. (1986). Development of respite services: Policy issues and options. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families*. (p. 289-305). Baltimore: Paul H. Brookes.

Key words: policy, program, family support

The author notes that a number of important policy choices will have to be made as demand for and availability of respite services increases. He points out that even though the attention of policymakers has been focused on deinstitutionalization and services to prevent reinstitutionalization, families still need support services whether or not the handicapped person they care for has been institutionalized. Respite services are discussed in the larger context of family support services. These services include transportation, recreation, information and referral and parent training, all of which help to maintain a person with a handicap in the home. Important policy considerations are involved when the family becomes the primary focus for services, as in the case of respite care. This focus represents a departure from the traditional focus on the person with a disability, with new ambiguities and complexities accompanying a service designed for the family as a whole. Noting that advocacy for respite services has increased among parents of children with disabilities and professionals working with them, the author discusses issues that

must be addressed in the development of programs and policies related to respite care. He lists five questions to be considered: (1) What policy objectives are expected to be considered? (2) What specific services will be provided? (3) Who will receive respite services? (4) How will they be delivered? (5) How will respite services be financed? It is noted that as more attention is given to respite care programming, its projected outcomes (such as strengthening the family and preventing institutionalization) will be increasingly questioned. The author maintains that accountability and reliable information will be expected from program planners and operators in order to demonstrate that goals are being achieved. This is especially the case because of ambiguous and uncertain support for family policy from legislators at various levels of government.

Specific service issues that involve policy considerations are described. These service issues include locus of service (in-home, out-of-home), accessibility to families, use of public facilities, and eligibility. Some of the related policy choices to be made are: (1) private vs. public service providers; (2) range of eligibility; (3) free service, cash payment, or voucher; (4) degree of family input and discretion; and (5) level of government responsibility.

The author also discusses respite program financing. State tax levy dollars currently constitute the largest source of funding for respite programs and other family support services. Federal initiatives, including the Home and Community Waiver (Sec. 2716, PL 97-35) and the Community and Family Living Amendments of 1983 (Sec. 2053), are described as potential sources for increased funding of respite services. According to the author, the role of local governments in funding respite services is uncertain, especially since their fiscal bases tend to be less stable. He raises the possibility, however, that respite services can be incorporated into other locally-provided services such as recreation and school programs (see Salisbury, "Generic Community Services as Sources of Respite"). Private sources of funding described for respite services are those generally provided through privately-purchased or employer-provided health insurance. The potentially large and long-term costs of respite care, though, have tended to be seen as prohibitively expensive or complex for most insurance plans. The author asserts that increased public funding of respite and other support services is a political demand related to public responsibility for the cost and risk of caring for persons with disabilities. He states that advocates must generate the political energy necessary to place the issue on the policy agenda. This article focuses on support services for families of children with developmental disabilities, but the issues raised are relevant to services for families of children with emotional handicaps. Planning respite services for these families also calls for involvement in the political process and consideration of policy issues.

Chock, P.N. and Glahn, T.J. (1984). Care provider and respite care services. In Christian, W.P., Hannah, G.T., and Glahn, T.J. (Eds.), *Programming Effective Human Services: Strategies for Institutional Change*. New York: Plenum Press.

Key words: program, training

This chapter addresses the need for training services for care providers, including natural parents, foster parents and respite workers. The authors maintain that such training is needed if disabled clients with special behavior or medical problems are to be served in the community. They also point out that adequacy of provider training has been a frequently cited concern among parents using respite services. A teaching curriculum used in community care facilities for the developmentally disabled is described, including supplemental training for respite workers. The authors point out that respite providers serve a wide variety of clients on a short-term basis, and consequently must acquire sufficient applicable skills. They identify several competency areas for workers. These include: (1) ability to assess clients' needs; (2) ability to carry out informal treatment; (3) development of generalized treatment plans; (4) working in groups; and (5) skill in daily routines. According to the authors, training in these areas is closely related to a respite program's level of accountability. They recommend that in order to maintain both adequacy of training and accountability, providers be required to: (1) complete an appropriate training course, (2) demonstrate competency on an annual basis, and (3) participate in refresher courses.

Cobb, P.S., (1987). Creating a respite care program. *The Exceptional Parent*, 17(5), 31-37.

Key words: program, program development

A respite care program providing in-home respite services is described. The author points out that more respite programs need to be developed, and offers a primer for doing so. Parents seeking respite services are encouraged first to survey what programs are available. If these are not appropriate or responsive to the family's or child's needs, efforts can be directed toward improving them. According to the author, working with an existing program is easier than starting a new one, although, initiating a new program may be necessary. Five steps for developing a respite program are described: (1) find other parents who are interested in developing a program; (2) involve people from local children's and social service agencies; (3) find some special education teachers and administrators who want to help; (4) involve politicians; (5) call other non-profit organizations to learn how they began. The author also points out the importance of conducting a needs assessment to determine what kinds of services parents want and will use. She adds that a needs

assessment may also positively influence funding sources. Suggestions are given for writing a grant proposal to fund services, and for incorporating as a non-profit organization. Cobb recommends that new programs serve five to ten families initially, and expand slowly. She also points out the importance of educating the public at large about the need for respite services, and doing so in such a way that they will want to help.

Cohen, S. (1982) Supporting families through respite care. *Rehabilitation Literature*, 13(1-2), 7-11.

Key words: general, policy, funding

The author begins by noting that one way many parents limit the tedium, exhaustion and stress of full-time child care is by taking time away from their children. She also points out that such natural relief periods are often not available to families, especially families with a handicapped child. The deinstitutionalization movement appropriately keeps more children with disabilities in their homes, but is not accompanied by sufficient support services for the parents of those children. The author states that families should not be expected to meet all the extra demands of caring for a child with severe handicaps alone. To do so increases the risk of family disintegration and child abuse. Funds must be allocated for developing resources specifically designed to support parents in this task.

Respite care is one resource for parent support. Cohen discusses various forms of respite services and their advantages. She points out that in-home services are most often preferred by families, but that a variety of program types are required to fully meet existing needs. Resources and services that are secondary sources of respite (i.e., do not have a primary goal of providing relief) are also described. The author maintains that inadequate funding for specifically-designed respite services makes the use of these secondary resources particularly essential. Referring to a 1978 study by the federal government, Cohen notes the researchers' finding that families most often using respite services were likely to: (1) have a second severely disabled individual in the home, (2) have a child with a disability whose care is extremely burdensome, and (3) lack a network of persons outside the home to call on during times of special stress. The study also found that respite care improved family functioning as perceived and reported by parents. Parents' mental health and social relationships were particularly improved. Twenty-five percent of the families using the services would probably have been unable to maintain the child in the home without respite care.

The author also discusses areas of respite care services needing improvement. For example, families often find the respite care times allotted by agencies are too short

in duration. Families also identified respite care workers' skill and training as in need of improvement. This is especially true for workers dealing with severe medical or behavior problems. A third area in which parents saw need for improvement was choice in types of service. Too often only one type of service was available, while a continuum of respite care services is required to truly meet family and community needs. The author maintains that a major problem with respite care is that there is not enough of it. She identifies this as a result of the absence of a stable funding base. Potential sources of funding are identified, but Cohen asserts these should be supplemented by legislation providing support to community-based, non-institutional services, including respite care. She calls for parents and professionals to mount a concerted effort to inform legislators, government officials, and the general public about the need for these services.

Cohen, S. and Warren, R.D. (1985). *Respite Care: Principles, Programs and Policies.* Austin, Texas: PRO-ED.

Key words: general, program, policy, training

This book provides a comprehensive overview of respite care for caregivers of individuals with developmental disabilities. The literature on family needs and policies is reviewed, followed by a discussion of respite care in the context of family support services. Analysis of the research on respite care and its implications for programming is presented. The authors describe various types and variations of program models, and include information for contacting agencies and providers. Policy, implementation and program issues are considered, including funding resources and existing and emerging legislative supports.

One chapter addresses the recruiting, training, and supervision of respite workers. Another chapter reviews respite care for families of dependent populations other than the developmentally disabled (i.e., families of the frail elderly, the physically handicapped, the mentally ill, and children at risk of abuse). The book contains an appendix which is essentially a manual for establishing respite care programs. This appendix describes steps of initial planning and implementation processes and includes sample forms and questionnaires. Even though the primary focus of this book is on respite care provided to those caring for persons with developmental disabilities, it offers a useful overview of issues and considerations important to planning and implementing programs for a wide variety of caregivers.

Curran, N.Q. and Bongiorno, H.H. (1986). Parents' perspectives: Focus on impact. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Disabilities and Their Families*. (p. 305-308) Baltimore: Paul H. Brookes.

Key words: parent input, program

The authors, both parents of children with developmental disabilities, discuss the unique nature of each person's and family's response to respite services. Seven suggestions are offered for parents: (1) use respite services; (2) design respite services so they fit parent needs, and the need of the person with handicaps; (3) use good baby-sitters, who may be eligible for training by a respite agency, since it is important for parents to feel comfortable with the worker; (4) listen to the sensitivities of the children, who will give clues as to the design respite services must take to be successful; (5) evaluate the experience informally after each respite so that information can be gathered to use for the next planned respite; (6) plan respite times, know when needs for a break will arise; and (7) do not wait for extended family to offer assistance before taking a break. It is a bonus when offered but there are many benefits to the less emotional and more businesslike nature of formal respite services. The authors point out that parents should not be afraid or embarrassed to seek help, including respite care, for themselves or their child.

Curran, N.Q. and Bongiorno, H.H. (1986). Parents' perspectives: Focus on providers. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families*. (p. 235-241). Baltimore: Paul H. Brookes.

Key words: parent input, training

The authors discuss respite service issues related to provider training and cost. They describe in-home services as being preferred by many parents, while calling for the development of a wide variety of types of respite care. Suggestions are given for provider training components that should occur before clients are served. These are: (1) an overview of handicapping conditions and their effect on the child and his or her family; (2) a clear description of what is expected at the placement; (3) a discussion of the agency's guidelines for the kinds of activities in which the respite worker can participate (e.g., taking the child in his or her own car, taking care of other siblings); and (4) some suggested activities to do with children or young adults with disabilities. Also suggested are courses in family counseling, care of the handicapped, family crisis intervention, pharmacology, and sensitivity and awareness training in the special needs and pressures of parents who have children with handicaps.

Informal training given by parents to providers at the start of the placement is also recommended. The authors suggest: (1) a brief overview of the parent's expectations, including ways to assure that the child enjoys the respite care time and that regular family routines around eating, television and bedtime are followed; (2) a review of the child's usual planned activities and a discussion of new possible activities mutually worked out between parents, the child, and the respite worker; (3) a list of emergency numbers to call; and (4) a discussion of the use of the child and his or her siblings as resources for information. The final suggestion has the benefit of drawing positive attention to the child, and may enhance the child's perception of the respite worker as a companion/friend. The authors maintain that respite services should be provided at no cost. They compare the lower cost of support services for in-home care to the much higher cost of institutional care.

Curran, N.Q. and Bongiorno, H.H. (1986). Parents' perspectives: Focus on need. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families* (p. 89-96). Baltimore: Paul H. Brookes.

Key word: parent input

This chapter is written by two parents who have children with handicaps. They describe the experience of caring for a child with special needs, and relate the importance of respite services to families. Four major points parents and professionals should consider with respect to respite services are outlined. In one of the author's words, these are:

> (1) The major caregiver needs to feel that he or she is entitled to respite. There needs to be an understanding that this parenting job is more demanding than more typical situations. Lack of adequate services 'forces' parents and their child/adult with disabilities to spend more time together than is healthy for either one. This dynamic can increase the tendency toward dependency by the individual with disabilities and overprotectiveness by the parents. Respite care can help promote healthier individual and family functioning; (2) We need to know our own tell-tale signs of fatigue/stress. For me, my daughter's repetitive conversations can begin to annoy me; I have an increased lack of interest in my own activities and become overly concerned about details of her life. I know I need a break!; (3) We need to believe that respite care will be a positive experience for all, or at least the family members (primary caregiver and person with special needs) who need it most; (4) Decide the time needed for respite, and make the call to the respite agency. Do it!

Ferguson, J.T., Lindsay, S.A., and McNees, M.A. (1983) Respite Care Co-op: Parents Helping Parents. *Exceptional Parent*, 13(1), 9-15.

Key words: parent input, program

This article describes the Kalamazoo (Michigan) Parent Respite Care Co-op. The program was initiated in 1977 by parents of children with disabilities, and established through a collaborative effort with professionals. The authors discuss the structures, policies and procedures of the respite service. Children cared for through the co-op range in age from two to young adult and have a variety of disabilities. Respite periods can be as short as two hours or as long as thirty days, with all respite care provided by participating families. There is no charge for care; instead, respite time is exchanged among families. Hours of care given and received are recorded by a care manager who periodically gives each family a statement of their credit and debit hours. According to the authors, some parents are hesitant to use respite services due to discomfort at leaving their child with someone they do not know. They point out that this is somewhat alleviated in the co-op model by the parents' familiarity with each other, and by the support and information given to parents recently joining the program. This article provides an overview of the parent co-op model of respite care, including suggestions and points to consider in the establishment of new programs. The authors especially stress the need for parent and professional collaboration in implementing a respite service. The contents of this article are presented in greater depth by the authors in the book edited by Salisbury and Intagliata.

Franz, J. (1980). Being there: A 24-hour emergency crisis care center. *Children Today*, 9(1), 7-10.

Key words: crisis care, program

This article describes the Respite/Emergency Crisis Care Center (REC) in Madison, Wisconsin. The program was established by a coalition of day care centers, with the two principal goals of providing emergency care and preventing child abuse and neglect. The program provides short-term care (with an average stay of 24 hours) for up to 12 primarily pre-school children. The author points out that the center is a blend of several different kinds of services. Although it is not a day care center, a treatment center, a drop-in center, a foster home, a family counseling agency, or a shelter or runaway home, it does have aspects of all those facilities. A key factor in implementing the service was defining "emergency." The author refers to a center staff person who noted that families needed to access the service before problems disintegrated into emergencies. Therefore clients don't need to be referred, but can come to the door or call to ask for help. A wide variety

of stressful situations can lead to a child being accepted for care: a parent being called out of town, hospitalized, or incarcerated; intra-family violence calling for separate care for children; financial hardship or homelessness. In addition to shelter services for children a range of family counseling and support services are also offered at the center. Several suggestions from center staff are included for persons interested in developing similar programs. These are: (1) use existing community programs as a basis for a new center; (2) be aware that crisis care is different than day care; (3) listen to families; (4) provide consistent in-service training to staff; and (5) maintain mutual support among staff. Individual community needs and issues should be considered in developing a program.

Gafford, L.S. (1987). Respite Care. In Wallace, H.M., Biehl, R.F., Oglesby, A.C. and Taft, L.T. (Eds.), *Handicapped Children and Youth. A Comprehensive Community and Clinical Approach* (p. 239-250). New York: Human Sciences Press, Inc.

Key words: general, funding, program, effects on families

The author offers an overview of respite care for handicapped children and youth. The work of Wilker and Joyce on the impact of respite services on families is summarized (See Wilker, Hanusa, Stoycheff and Joyce, Singer). In home models of respite care (trained providers, homemakers, home health aides, and companion services) and out of home respite care models (trained providers serving in their own homes, weekend respite camps, respite foster homes, temporary group home placements and pediatric nursing homes or hospitals) are reviewed. Current funding sources are described.

Geiser, R., Hoche, L., and King, J. (1988). Respite Care for Mentally Ill Patients and Their Families. *Hospital and Community Psychiatry*, 39(3), 291-295.

Key words: program, family support, effects on families

An inpatient psychiatric unit at a Veterans Administration Medical Center offers regularly scheduled psychiatric respite care, an intervention intended to reduce recidivism among chronic patients who live with a family member and to support the family in their caregiving role. Patients and their families have the option of arranging for respite admissions for two to seven days at six- to eight-week intervals. Preliminary one-year data for 14 patients show that with participation in the respite program, subsequent hospital days are significantly decreased. Subjective data indicate that respite care helps stabilize improvements patients made in the

hospital, allows staff to work with family systems in a nonadversarial manner, and gives the family needed relief from difficult behaviors. (Author's abstract).

Glass, R. (1982) Meeting the program needs of women: Mainstream child care. *Rehabilitation Literature*, 43(7-8), 220-221.

Key word: policy

The author maintains that women in today's society experience higher levels of stress and anxiety. She notes, though, that support systems have not increased proportionately. Mothers of children with disabilities are described as being particularly in need of such support, and in need of breaks from the substantial responsibilities of caring for the child. The author asserts that child care must be made available to these families, ideally through mainstream child care centers. Employers, according to the author, not only have a responsibility to provide child care services but would benefit themselves by doing so. Federal legislation offering support or tax incentives related to child care services are also discussed.

Grayson, J. (1987) Respite: A caring response. *Virginia Child Protection Newsletter*, 21, Winter Bureau of Child Welfare Services, Virginia Department of Social Services: Richmond, Va.

Key words: general, crisis nursery, emergency care

This article provides an overview of respite services. After an introduction to the needs and reasons for respite care, three types of respite care services are described. These are: (1) crisis nurseries, providing care to children while family crises are defused; (2) respite services to families of a child with physical or developmental handicaps; and (3) respite child day care, providing care on a regular, planned basis to families considered at risk of abuse or neglect. Examples of all three types of programs are given, along with information on contacting those programs. Although the focus is on services in Virginia, programs from around the country are described. Recommendations are also included for starting new programs. This article provides a very good introduction to respite services.

Halpern, P.L. (1985). Respite care and family functioning in families with retarded children. *Health and Social Work*, 10(2), 138-150.

Key words: outcome, effects on families, program, stress

The author's study hypothesized that use of respite services would enhance the functioning of families with retarded children. The study also sought to determine the relationship between respite services and the ability of these families to recover from the stresses facing them. Thirty-one families who had and thirty-one families who had not used respite care services were compared on ten specific areas. Findings suggested that respite care was useful in maintaining family stability in certain areas such as level of conflict and organization. The author also points out the study's suggestion that low-income and minority families tend not to use respite services as frequently as those from higher economic and majority ethnic backgrounds. She recommends that outreach, accompanied by information and support, be offered to families who may be unaware or cautious about respite services. Outreach is also recommended for young families, and for families whose overall functioning requires improvement before respite services can be used. According to the author, social work involvement in addition to outreach is called for in several other areas of respite services. She calls for intake assessments to include information on the child's behavioral status, the family's existing support network, the family's perceptions of the stress it is facing, and the presence of additional sources of stress for the family. Teaching and supportive services are also described as supplementing respite care.

Humphry, G. and Labarrere, C. (1979). Respite care: A lifeline for the disabled. *Practice Digest*, 1(4), 7-9.

Key word: program

The respite care program provided by the Children's Home Society of California is described. A key feature of this program is the use of foster families for provision of respite services. Parents of children with developmental disabilities can apply for respite care through Los Angeles County's regional centers for the developmentally disabled. Once authorized, families are referred to the Children's Home Society with whom the county has a purchase-of-service agreement. Respite services are provided to the families free of charge for periods of twenty-four hours to three consecutive weeks. Prospective foster families are required to have previous experience with children. Screening procedures and home visits by a social worker are used to insure that respite providers are acceptable and qualified. The limitations of this model are also discussed. For example, about 5% of the children referred are rejected because of severe behavior or medical problems that cannot

be dealt with in the foster homes. Other limitations include an insufficient number of respite homes, and inconsistent and unstable funding.

Intagliata, J. (1986). Assessing the impact of respite care services: A review of outcome evaluation studies. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families*. (p. 263-288). Baltimore: Paul H. Brooks.

Key word: program evaluation

The author maintains that respite programs are widely believed to provide critical support and other benefits to families. He states, however, that the evaluation data that could substantiate those benefits and be used to justify the existence and expansion of respite services is limited in amount and sophistication. This chapter provides a conceptual framework for the evaluation of respite care services, describes previous evaluation studies, identifies existing gaps in the evaluation data base, and suggests types of studies to fill these gaps. The author lists seven reasons for evaluation of services: (1) to determine whether a program is developing in the right direction; (2) to determine whether a program is meeting the needs for which it was designed; (3) to obtain evidence that might help in demonstrating the effectiveness of a program; (4) to compare different program methods or approaches in terms of their relative impact; (5) to justify past or projected expenditures; (6) to gain support for program expansion; and (7) to identify those factors both internal and external to the program that facilitate or inhibit it in making its intended impacts.

The framework presented for evaluation of respite services has three major components: independent variables, intervening variables, and outcome variables. Independent variables are those clearly under the control of program providers, and can be used to describe and characterize services. These include the location in which respite is provided, the qualifications of respite care providers, the availability and accessibility of respite services to families, and the activities that take place between the respite care provider and the clients during respite. Intervening variables, though generally not under the control of program providers and evaluators, occur in the context of services and moderate or influence the impact of respite services on families. The intervening variables may include the characteristics of the family, the characteristics of the person with disabilities, the family's perceptions of the quality of service, the availability of other programs and supports needed by the client and family, the conditions under which respite services are requested, and how families use their time when receiving respite. Outcome variables are the promised results of the program. These include the degree of utilization, reduction in levels of stress felt by families, improvement in families'

mental health and quality of life, reduced social isolation and increased social activity, development of more positive attitudes toward the child with disabilities, and reduced likelihood of out-of-home placement. The author assesses the extent to which achievement of these outcomes has been demonstrated by various studies, and how the independent and intervening variables influence whether such outcomes will be realized. He concludes that evidence in the literature supporting the benefits of respite programs has been generally weak, and that higher quality studies and evaluations need to be carried out.

Joyce, K., and Singer, M. (1983) Respite care services: An evaluation of the perceptions of parents and workers. *Rehabilitation Literature,* 44(9-10), 270-274.

Key words: training, workers

The present study examines a respite care program with respect to the training and job attitudes of respite care workers and the perceptions of families who received respite services. Significant findings include: (1) training sessions for respite care workers significantly enhanced their knowledge in the field of developmental disabilities; (2) families whose children were recently disabled reported receiving more benefits from respite services than families whose children had been disabled for a longer period of time; (3) respite services were most effective in providing emotional relief for parents and in allowing parents to pursue activities which would have otherwise not been possible; and (4) many families who considered institutionalizing their disabled child believed respite services enabled them to care for their child at home. (Authors' abstract).

Levy, J.M. and Levy, P.H. (1986). Issues and models in the delivery of respite services. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families* (p. 99-116). Baltimore: Paul H. Brookes.

Key words: policy, program, planning

This chapter discusses the critical issues related to the provision of respite care to developmentally disabled persons and their families; it includes a brief review of research on respite services; an examination of a variety of respite models; a description of the Young Adult Institute's Respite Project; an analysis of philosophical, staffing, fiscal and legal concerns that can impede implementation of

these services; and recommendations for future efforts in the development of respite services. (Authors' summary).

The authors point out that in spite of the deinstitutionalization of persons with disabilities, home-based services receive less than 1% of the total federal budget expended for health and social services. Since more individuals with disabilities live in their natural homes, they maintain, society must now meet the challenge of creating a comprehensive array of services designed to meet the support and relief needs of families and caregivers. Respite care is described as among the most basic of these needs. The author describes two kinds of respite: primary sources of respite which have as their main objective providing relief to the family; and secondary sources of respite (such as schools and camps) which, while still providing relief to families, do not have that as their primary purpose. Several ways of providing respite services are described, with a discussion of the advantages and disadvantages of each. Included are in-home and out-of-home respite care. In-home services may include: homemaker services, sitter/companion services, or parent trainer services that train relatives or other individuals chosen by the family to be care providers. Out-of-home services may include: licensed foster homes, parent cooperatives, respite providers' homes, day drop-off centers, established residential programs, institutional care services, or respite residence models designed specifically for provision of respite.

In discussing the respite program of the Young Adult Institute in New York City, the author defines a number of issues related to developing a respite program. These are: (1) What respite services are currently being provided in the area?; (2) What are the needs of the community to be served, and has community input been incorporated into planning services?; (3) What services can realistically be provided within the parameters of the projected budget?; (4) Will respite care be provided in or out of the family home, or both?; (5) Are the proposed services accessible to families?; (6) What means of outreach will be utilized to make families aware of the services?; (7) What criteria will be used for determining family eligibility?; (8) How will staff be recruited, trained, and supervised?; (9) Will workers be paid or recruited as volunteers?; (10) What health and safety issues need to be addressed?; and (11) What liability and insurance issues need to be considered? The author addresses fiscal issues related to respite services, especially the disparity between higher institutional care costs and the lower costs of home care. He notes that inadequate funding mechanisms are the major barrier to provision of respite services. Funding strategies vary from state to state, leading to inconsistent services between states. The federal Medicaid Home and Community-Based Waiver Authority, paying for home-based care in certain cases, is considered by some professionals to be a promising resource for future funding.

Maine Respite Project. (1987). *The Maine Respite Project Manual.* Bangor: Author.

Key words: program, program development, training, policy

The Maine Respite Project is a new federally funded three year project offered through the Bureau of Children with Special Needs/Maine Department of Mental Health and Mental Retardation. Project goals include: (1) initiating a public education campaign about respite services for families whose children have developmental disabilities; (2) developing a thirty-eight hour training and certification program for respite providers; (3) establishing a statewide information and referral network; (4) promoting family supportive public policies; and (5) promoting interagency coordination. The manual is designed to serve "as a useful guide to individuals and agencies seeking to replicate the successful elements of the Project." The project targets rural families who have children under twenty years of age with developmental disabilities. Among others, the forms contained within the manual include: intake, family application, medication, billing, and accident/illness reporting forms. Public information and awareness brochures, public service announcements and presentations are described. Respite care licensing, insurance and operational policies are discussed. The respite care training curriculum developed at the University of Missouri-Kansas City and employed by the Maine Respite Project is summarized (See University of Missouri-Kansas City).

Milne, M. (1986) Kids and parents spell relief NURSERY. *Children Today*, , 15(5), 13-16.

Key words: program, crisis nursery

The Lane County Relief Nursery, an Oregon program working to prevent and alleviate child abuse and neglect, is described in this article. The author discusses the program's goals, structure, and clients. The nursery is housed in two local churches and includes a therapeutic preschool program. Seventy-two children, most referred by Children's Services Division (CSD), the state child protective service agency, are served. Five paid staff members, supplemented by 39 volunteers, operate the program. In conjunction with the nursery, a parent training program is provided by CSD. The author describes and gives case examples from this training program. Funding issues related to the nursery are also discussed. The author notes that the program's low budget and its heavy reliance on volunteers contributed to its being selected by the National Committee for Prevention of Child Abuse as one of 26 national program models.

Neef, N.A., Parrish, J.M., Egel, A.L. and Sloan, M.E. (1986) Training respite care providers for families with handicapped children: Experimental analysis and validation of an instructional package. *Journal of Applied Behavior Analysis*, 19(2), 105-124.

Key words: training, research, workers

Four experiments designed to evaluate a respite care training package are described. Experiment One assessed the effectiveness of a self-instructional training manual for acquiring respite care skills. It compared three different manual formats: with concepts supplemented by written examples, by pictures, or both. The authors found that trainee performance during simulated (role-played) respite care situations improved substantially for all participants following use of the instructional manual. There was no significant difference noted between formats. Experiment Two evaluated the effects of the training manual in its complete format, and compared it to a workshop training approach. The authors found both the manual and workshop approaches to be effective, but found that use of the manual alone was more cost-effective. The primary purpose of Experiment Three was to assess a simplified training and evaluation package that would be practical for respite agencies to implement. Participants' (all of whom had recently completed an agency's respite care training program) scores on a test of respite care skills increased after using the instructional manual. Skills were further tested, and specific areas of deficiency identified, through simulated respite situations. The authors maintain that this underscores the importance of objectively evaluating trainees' respite care skills, rather than assuming those skills are gained in workshop settings. Experiment Four was designed to determine the extent to which the training and evaluation procedures could be implemented effectively by respite care agency personnel. Participating agency staff were able to implement the program during the experiment, and subsequently adopted the training/evaluation package. Suggestions are given by the authors for developing training curricula. They also point out the benefits of on-going assessment and remediation of trainees' skills, which they say should supplement presentation of a stock training curriculum. Another recommendation is the use of an advisory board, made up of professionals with various specializations, in the development of the training manual. The information in this article would be of use in developing new training programs, or in enhancing existing curricula.

Parrish, J.M., Egel, A.L., Neef, N.A. (1986). Respite care provider training: A competency based approach. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families* (p. 117-142). Baltimore: Paul H. Brookes.

Key word: training

The authors discuss the importance of adequate training to the overall effectiveness of a respite care program. A study is cited which suggests that the availability of well-trained care providers is an important factor in a family's decision to use respite services. Another study found the most common reason for dissatisfaction with services is inadequate provider training. According to the authors there is a clear need for better training of respite workers. The authors call for "competency-based care" (p.119), which would involve training in specific relevant skills. The following characteristics of effective training were identified: (1) experimentally validated; (2) accessible to the lay person so that it can be used by a broad range of programs and providers; (3) designed so that lay persons and paraprofessionals are not overly reliant on professionals; and (4) gives consideration to the cost-effectiveness and ease of dissemination. The authors also recommend that training be applicable to a range of clients, and that follow-up training related to specific handicaps or situations be provided by parents and other resources.

Several training approaches are presented, with a discussion of the advantages and disadvantages of each. Suggestions for enhancing these approaches are also given. The authors note that evaluation of workers, with collection of pre- and post-training data, is important to a training program. Providers can use evaluations to identify skill areas in which they are particularly strong and those in which they need improvement. In addition, the authors note that pre-test data can provide a standard against which the effectiveness of the program might be judged. Methods of evaluation presented and critiqued are: (1) written quizzes; (2) role playing; (3) a combination of quizzes and role playing; (4) having skilled care providers accompany trainees in actual respite care situations; and (5) feedback from parents. The chapter closes with a discussion of future directions for the training of respite care providers. Training issues include: training of program coordinators in instructional technology; exploring alternative training formats; experimental validation of training programs; devising formats that can be easily replicated and disseminated; and certification of respite workers.

Powell, T.H. and Ogle, P.A. (1986). Brothers and sisters: Addressing unique needs through respite care services. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families* (p. 29-50). Baltimore: Paul H. Brookes.

Key words: siblings, program, rationale

The authors note that the sibling relationship is one of the most influential and long-lasting relationships in an individual's life. They point out that with the increased emphasis on keeping children with handicaps in the home there has been an increased recognition that brothers and sisters play a critical role in the overall development of children with handicaps. Siblings need special community services - especially respite care. Research shows that the relationship with a brother or sister with a handicap can have both positive and negative effects on siblings, with effects varying for individuals at different times. There may be a healthy positive relationship at one time, and negative behaviors and feelings at another. Four factors are identified that influence the sibling relationship and affect sibling adjustment. These are: (1) family characteristics, including family size, socioeconomic status, and religion; (2) parental attitudes and expectations, (clearly a significant influence on a sibling's acceptance of a child with handicaps); (3) characteristics of the non-handicapped sibling, especially gender and age in relation to the child with a handicap; and (4) characteristics of the handicapped child, including the severity of the handicap and age of the child. The authors describe the critical transitions faced by families of children with handicaps. Especially important are those which occur when: the parents initially find out the child has a handicap; the child with a handicap becomes of school age; the child leaves school and faces the normal difficulties of adolescence; and, the parents age and need to address the concerns of how the child will be cared for without them. These factors serve as a framework to help service providers know when a family may experience the most stress and where to direct services in order to minimize family problems. Respite services are identified as one way of avoiding potential difficulties, and as having a profound influence on family members. It is pointed out that these are also critical times for the sibling relationship.

The authors describe five major ways that respite care can assist siblings: (1) renew relationships with parents; (2) provide time for special activities; (3) allow siblings time for themselves; (4) take short vacations; and (5) keep the family system intact. Roles for siblings in respite services are described as: (1) providing information on respite needs; (2) evaluating respite services; (3) serving on boards of directors (especially older adolescents and adults); and (4) training respite providers. Using siblings as respite providers is also discussed, with the caution that they not be precluded from the benefits of respite care programs. The authors recommend that siblings be encouraged to utilize natural opportunities for respite. These may be clubs and sports, school (where they should not be expected to care for a brother or sister with a handicap), friends, and relatives. More research is called for to

determine the impact of a child with a handicap on his or her brother or sister. To supplement information from existing research, the authors provide statements from siblings who share their experiences and reactions to having a child with a handicap in the family.

Ptacek, L.J., Sommers, P.A., Graves, J., Lukowicz, P., Keena, E., Haglund, J., Nycz, G.R. (1982) Respite care for families of children with severe handicaps: An evaluation study of parent satisfaction. *Journal of Community Psychology*, 10(3), 1982.

Key word: parent input

Respite care services provided in foster homes to 68 children with severe handicaps were studied to determine parent satisfaction. The authors describe the need for respite services to families who care for a child with handicaps, noting that respite services can result in family revitalization and a fresh outlook for the continued care of the member with a disability. The development of respite services is described as having been sporadic. This is attributed to the lack of a contemporary definition of respite and the lack of legislative support. Both are essential for the establishment of sound programs and fiscal independence for respite services. The authors call for consumer input into the development of respite policy and service delivery. The authors monitored parent satisfaction and gathered feedback for program development and implementation. The evaluated program provided respite care by foster parents in their homes for periods of two to fifteen days. Families could use the service as often as necessary. After they received respite services parents were surveyed by written questionnaire. Results from the survey indicated that parents had positive opinions about the delivery of respite services. Parent recommendations included: (1) providing respite care at low rates; (2) recognizing that every parent needs a break from the on-going requirements of a child with a handicap; and (3) other forms of respite, notably in-home services, need to be developed.

Salisbury, C. (1986). Generic community services as sources of respite. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families*. (pp. 195-216) Baltimore: Paul H. Brookes.

Key words: secondary respite services, community services

Generic services are defined as typical services that families with non-handicapped children either receive outright or are able to purchase for a standard price. Examples are medical, dental, child care, financial, educational, mass transportation, and recreational activities. The author points out that these resources often serve as sources of "secondary" respite, even though relief for caregivers is not their primary purpose, and should include persons with disabilities. Community resources are described as facilitating social participation, social control, mobility, and social and political expression. They are also seen as forming the social context within which a family operates. However, the author notes that these resources are often unable or unwilling to serve individuals with disabilities. Thus, the social supports and networks of these individuals' families are frequently constricted, leading to higher incidence of stress and isolation and fewer outlets for relief and renewal. The absence of resources may also lead to increased dependency of the person with disabilities on the family. The author discusses the discrepancy found in many communities between expectations for normalized services for the handicapped and what exists in practice. The dual system, she maintains, sets up artificial barriers between people with and without handicaps. Four reasons for removing these barriers and integrating persons with disabilities into community services are given: (1) development and support of specialized community services are costly, and their quality is often not equivalent to comparable programs in the general sector; (2) the capability for modifying community resources has been demonstrated, as in the case of the elderly and physically handicapped, and should now be expanded; (3) the long-term social costs to persons with disabilities appear to be far greater when only specialized services are available, which presents long-term consequences for all members of the community; and, (4) provision of integrated services serves to broaden the social supports and networks of all families in the community. The author asserts that use of community resources as social supports for families of individuals with disabilities can only be achieved when such resources are readily available to those families. Both formal and informal resources and networks should be encouraged as ways of providing respite to families.

Salisbury, C. (1986). Parenthood and the need for respite. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families* (p. 3-28). Baltimore: Paul H. Brookes.

Key words: general, rationale, literature

A review of the literature related to family stress and coping is presented, including research on families with handicapped and non-handicapped children. The author maintains that understanding patterns of stress and coping found within any family helps one understand those patterns in the family of a child with special needs. Parenthood is described as creating structural and functional changes in the family unit which can be highly stressful. The effects of stressors can be mitigated by parents' own coping mechanisms, interfamilial assistance, and extrafamilial social supports. Adjustment to parenting can be seen as an interaction between personal, family and community variables. Although research has shown social support and social networks to be related to coping ability, these are not always available to parents, in particular to parents of children with handicaps. The quality of a community's resources are described as playing a key role in supporting families. Insufficient services can produce hardships for families already facing stressful life events. Among the families seen as most vulnerable and in need of support are those dealing with a member requiring long-term care or whose care demands large amounts of time. Thus, parents of children with handicaps need community support services to ameliorate the effects of caring for a handicapped child. The author notes that although the literature shows these families typically experience more stress it is inappropriate to label them as "extraordinary" or their coping mechanisms as "deviant." This is especially true since they often cope and adjust with few options for social supports. Respite should be understood in the context of providing needed social and family support services. The author maintains that respite care is a service that can help mediate stressors, and a service that is appropriately demanded by parents.

Salisbury, C.L. and Intagliata, J. (Eds.) (1986) *Respite care: Support for persons with developmental disabilities and their families.* Paul H. Brookes: Baltimore.

Key word: general

This book provides what may be the most comprehensive overview of respite services currently available. Contributors from a range of backgrounds provide extensive information on the rationale for respite services, policies related to respite services, types of respite programming, parents' perspectives, program evaluation, provider training, and other areas. The book's contents are well-grounded in theory and research, and coalesce around the theme of the need for more and better

respite services. Although written with a primary focus on services to families of children with developmental disabilities, the information presented is applicable to respite care planning for other populations, including families of children with emotional handicaps. For summaries of specific chapters see: Salisbury (need for respite, and community services as sources of respite); Powell (sibling issues); Slater (national overview); Curran and Bongiorno (parent perspectives); Levy (program models); Parrish (provider training); Wikler (relationship of respite to the reduction of family stress); Intagliata (evaluating services); and Castellani (policy issues).

Shettle, K., Gallin-Kremer, E., Witzel, C., Keating, D., and Klaber, M. (1982). Staff development in a community-based respite program. *Child Welfare*, 66(3), 161-170.

Key word: training

The staff training and development component of a respite care program serving severely disabled children is described. The authors point out that one of the most vulnerable components of any program is its child care staff. Because work with severely handicapped children is particularly demanding, this staff training program is designed to provide specialized skills and to prevent staff turnover and "burn-out." The training program takes place at a multi-service community mental health agency, the Wheeler Clinic in Plainville, Connecticut. Respite services are provided both in the agency and in the families' homes. Children with a variety of disabilities receive care. They range in age from infancy to adolescence. Providers must be able to plan and direct activities for many different kinds of needs and situations. According to the authors few professionals have both the specialized training and breadth of skills needed to staff this type of program. In addition, they point out that workers in the child care field tend to use jobs as "stepping stones" to positions with more growth potential. For these reasons a training program was developed that would serve two primary purposes: (1) to train workers to meet particular job roles and responsibilities of the program; and (2) to provide supervision supports that would help maintain motivation, job satisfaction, and opportunities for growth and advancement. Several levels of staff were created, with roles and responsibilities defined for each level. Administration, scheduling and supervision are carried out by the program director and senior counselor. Direct care is provided by counselors, alternate counselors (on-call staff available during high-use times), and volunteers who serve as aides to the counselors in the agency setting. The authors state that the most crucial aspect of the training program for these staff is that it be an on-going educational and supportive experience.

Training is organized into three components: (1) orientation, during which details of the respite program and overview of the disabilities served are given; (2) supervised

experience, including (for counselors) forty hours of direct work with children, and direct supervision throughout their stay for volunteers; and (3) in-service training, held weekly for a minimum of two hours. Besides expanding and refining the skills learned in previous training, in-service sessions are designed to address needs and issues raised by child care workers. Topics may range from skills needed to work with a specific new client to concerns about staff relationships, communication, and professional conduct. Training is provided by an experienced agency staff member who is not part of the agency's personnel or evaluation systems. This facilitates open communication and honest sharing of problems, concerns and grievances. The effectiveness of staff development activities is evaluated in three ways: (1) informal feedback from child care workers; (2) on-the-job observation by the staff trainer; and (3) a questionnaire administered prior to training and after six months of participation in the program. The authors see the staff development program as a success, which they attribute to its flexibility, provision of on-going support, and clear designation of roles and responsibilities for each position.

Slater, M.A. (1986) Respite care: A national perspective. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families* (p. 69-96) Baltimore: Paul H. Brookes.

Key words: emotional/behavior problems, groups not served, policy

The author provides an overview of current respite care efforts, focusing on the findings from three major studies. Areas described are: (1) types of services; (2) funding/costs of services; (3) client characteristics; (4) use of respite programs/services offered; (5) staff/staff training; and (6) implementation problems. Study findings identify three significant problems related to respite care: (1) family reluctance to use respite services; (2) difficulty in recruiting and retaining respite providers due to low pay and time required for training; and (3) denial of services to families of individuals with emotional or behavioral problems. The researchers also found that families using the existing natural family network for respite care would prefer to continue doing so. Families were therefore most drawn to programs allowing them to choose the respite provider (including relatives and friends) who was then paid by the respite care agency. Families surveyed indicated that they would use a wide variety of types of respite services, and that a variety is needed to allow for flexibility and accessibility. Particularly mentioned was the need for home-based care which permitted the child to remain in his or her natural surroundings. The author notes that when given a choice, families elect to deal with concerns in as normalized a fashion as possible, and that what is needed now is social support for doing so. She calls for fully developed family support programs, including respite care and family assistance. Family support programs need to

involve the use of informal social supports, as well as family empowerment and input into planning services.

Subramanian, K. (1985) Reducing child abuse through respite center intervention. *Child Welfare*, 64(5), 501-509. Child Welfare League of America.

Key words: crisis care, crisis nursery, stress

The prevention of child abuse has been the major goal of the crisis nursery or emergency respite care type of respite program. These programs are designed to provide shelter to children when their parents are unable to care for them, or when parents or others feel that the child is at risk of abuse or neglect. The author presents a study of the relationship between stress reduction in families and provision of respite services at an emergency respite care facility. The author refers to literature showing a relationship between parental stress and child abuse, noting that children are often the targets of displaced anger or frustration. Recent research cited indicates that chronic, on-going stresses significantly influence the ways that individuals deal with larger life events. The author asserts that potentially abusive parents must have relief systems available to them at critical moments of stress. According to the author, emergency crisis respite services have the goals of providing a safe environment for the child and providing a non-threatening resource for parents. Respite care is described as a form of home-based care in which help is available before the last resort is reached. In the study presented, parental stress was reduced by respite care, and further findings supported the belief that respite care served to prevent child abuse and neglect. Recognizing that it is difficult for service providers to have an impact on clients' major life changes, the author points out that providers can address significant on-going pressures through respite care services.

Sullivan, R.C. (1979). Parents Speak: The Burn-out Syndrome. *Journal of Autism and Developmental Disorders*, 9(1), 111-126.

Key words: policy, parent input

This column discusses the "burn-out syndrome" experienced by many parents of autistic children. Following the author's comments, two parents of autistic children and three professionals in the field of autism respond. The burn-out syndrome is defined as the exhaustion of a person's psychological and/or physical resources, usually after long and intense caregiving. The author asserts that both the causes and cures for burn-out are known, and cites the lack of respite services as one of the

best-known causes. Examples are given of parents who have not gone out together since the birth of the child with a disability, parents sitting up all night with a screaming child, and parents who cannot find baby-sitters even among close relatives. The author maintains that an impediment to the development of respite care is the tremendous psychological resistance to the idea that the state has a moral responsibility to help families who need such services. The government provides what we cannot provide for ourselves (schools, roads, etc.), and the author states that this role should also include assisting families in crisis. Although most parents of autistic children want to keep their children at home, states will spend tens of thousands of dollars for institutional care while refusing to grant a few hundred dollars for family relief. The author calls on parent and consumer groups to persist in their demands for respite services. Causes of burn-out other than lack of respite are also discussed. These include inability to effect significant change in the life of the autistic child, and lack of adequate coping skills. The author asserts that professionals should recognize that people handle stress in different ways. Therefore, demands should not be made of parents without considering their willingness and ability to respond, as well as the costs to them and other family members.

Terkelsen, K.G. (1984). *Training Curriculum for Respite Providers for Families of Mentally Ill Young Adults.* Valhalla, N.Y.: Westchester Self-Help Clearinghouse.

Key word: training

The training curriculum includes tools for recruiting providers (newspaper ads, telephone screening outline, respite provider intake interview) and family intake and emergency medical treatment consent forms. Suggestions are offered on how to prepare for the training program (staffing, training space, supplies and equipment) and a sample training program agenda in included. The following eight training modules are presented: (1) overview of respite services; (2) causes of mental illness; (3) manifestations of mental illness; (4) treatment of mental illness; (5) an overview of the family's experience of mental illness; (6) a "practicum" meeting and discussion with a family to discuss their experiences with a mentally ill family member; (7) strategies for beginning a relationship with a mentally ill person; and (8) basic medical issues and home safety.

University of Missouri-Kansas City. Institute for Human Development. (1984). *Respite Care Training Package.* Kansas City: Author.

Key word: training

The overall purpose of the training program is to provide individuals, who have little or no previous knowledge of developmental disabilities, with basic knowledge and skills which will enable them to provide respite care to clients of a variety of ages, abilities and handicapping conditions. It is recognized that the delivery of such care may vary from locality to locality dependent upon the administrative structure, community resources and client needs. This program is designed as an entry level training program and specialized needs of individual clients must be added to the training program. However, such customization should take place only after the participant has demonstrated competency in this core material. The following is a description of each of the three components of the training package.

The Training Program Guide serves as the basis for the planning and conduct of the overall training program. Such topics as an introduction to the training package, competency-based training, training agreements, conduct of the workshop, evaluation of training outcomes, and approach to system implementation are discussed. The guide is designed as a planning tool for the singular person who assumes overall responsibility of the training program.

The Instructor's Lesson Plans consist of ten modules which comprise the training program. Since this material is considered to be the minimum acceptable to ensure competency, it is the intent of the authors of this curriculum that all ten modules be taught. The modular format is used to allow for flexibility in the scheduling and sequencing of the material. A variety of different schedules., i.e. one weekend workshop and biweekly evening sessions, may be used to cover the material. The times which are provided in this material serve as general guidelines only and are not rigid requirements. The overriding consideration is whether the providers, once they have completed training can satisfactorily demonstrate attainment of the prescribed objectives. While individual modules may also be useful for other applications, once again, they are designed as an integrated training package.

The Student Manual is designed as a resource for the participant. It is recommend that the student read the specific module information before the training session. It parallels information outlined in the Instructor's Lesson Plans. It serves to increase the learning and retention rate during the training, and as a reference manual after the training. (Authors' summary).

Upshur, C.C. (1982) An evaluation of home-based respite care. *Mental Retardation*, 20(2), 58-62.

Key words: evaluation, behavior problems, training

The evaluation of a home-based respite care program is discussed in this article. The evaluation demonstrates that families of individuals with severe behavior or medical problems can be provided with respite care services. The author refers to earlier studies that found that families prefer to use in-home respite services. Those with members who had severe disabilities or behavioral difficulties, however, were often excluded from receiving services. The author points out that those families are often most in need of respite. The pilot project described in this article attempted to meet family preferences for in-home services while providing specialized training and other supports to workers. This enabled more severely disabled clients to be served. Case examples from the project are presented, illustrating the severity of behavior problems involved. When the project was evaluated, families gave it high satisfaction ratings. The author reiterates the benefits of in-home respite services, including the cost-effectiveness crucial during periods of low funding. She maintains that the success of the pilot project indicates that consideration should be given to expanding service models to include a wider range and degree of disabilities.

Upshur, C.C. (1983). Developing respite care: A support service for families with disabled members. *Family Relations*, 32, 13-20.

Key words: general, program

The author points out that respite care is a concept which has been developing since the late 1960's, but is only recently beginning to obtain the attention and support it deserves. She asserts that respite services are not available on a wide enough scale nor or they recognized as a necessary element of support services for families caring for a person with disabilities at home. A survey of twenty-four states is cited which revealed that only a few had state respite services, policies, and funding in place. Guidelines for respite services from some of these states are summarized. According to the author, clients with behavior problems and other special needs are often excluded from services, even in states where respite services are somewhat developed. Thus, families with the greatest need are often left with the fewest alternatives. The author refers to research on family stress, particularly families with handicapped children, which demonstrates the need for respite services to those families. She maintains that despite this obvious need, little attention has been paid to developing quality program models, providing adequate funding mechanisms, or informing parents and professionals of existing approaches.

Four major types of respite care models are identified, with discussion of the advantages and disadvantages of each. The four types are (1) home-based care, (2) group day care, (3) residential respite care, and (4) programs providing respite care as an adjunct service. Home-based care can be delivered through agencies which recruit, train and place workers, or which serve as "funding conduits" that reimburse families for respite care they arrange on their own. Care can be given in the client's or provider's home. According to the author major advantages of home-based care are flexibility in serving different ages and disabilities, and cost-effectiveness brought about by few fixed costs and providers being paid only when delivering services. Limitations of home-based care are lack of back-up services, and difficulty accessing services in an emergency or for long periods of time. In addition, many clients cannot be served by non-professionals.

Under the group day care model clients are provided daytime activities in a specific location, freeing the caregiver's time for the day. Advantages of this type of respite care include the possibility of regular and frequent relief periods, and the provision of more intensive services. Disadvantages are difficulty in meeting a wide range of client needs, potential transportation problems for families, and high initial costs for staffing, space and equipment. Once initial costs are paid, though, this model may have lower costs-per-client than home-based care.

Residential respite care facilities are designed solely to provide respite care to small groups of persons with disabilities. These programs are able to provide more intensive services to medically or behaviorally difficult clients and have more extensive back-up services. They are limited, though, in the ages and types of disabilities they are able to serve. Another disadvantage is high start-up and operating cost.

Programs providing respite care as an adjunct service make up the fourth model. These programs may be community residences or group homes, various institutional types of care, nursing homes, and long-term state institutions. Using these types of programs for respite care has the advantage of accessibility in emergencies, intensity of services, ability to serve clients with severe behavior problems, and availability of long-term care. Disadvantages are possible disruptions to resident clients and program, limited flexibility in range of clients served, and family reluctance to use an institutional setting even for a short time. The author concludes that a combination of these approaches will have the best chance of meeting the needs of families and communities. While calling for both emergency and planned respite care services, she notes that the preferences of families toward home-based care should encourage the development of less institutionally-oriented models.

Warren, R. and Cohen, S. (1985) Respite care. *Rehabilitation Literature*, 46(34), 66-71.

Key words: general, rationale, policy

The authors define respite care as a temporary relief service for families or primary caregivers, pointing out its unique feature of being a service to the caregiver rather than just to the person with a disability. They maintain that the deinstitutionalization and normalization movements for the developmentally disabled have brought a heavy burden of care to communities and threatened existing family resources. Caring for a person with disabilities in the home requires personal resources such as good physical and mental health, an emotionally strong and stable marriage and family interaction, a support network of family and friends, time and skill in negotiating the service system, and money. Respite care is one of the support services needed to ensure that these resources are intact. Guidelines are suggested for program models. These guidelines include: (1) providing an array of services to match family needs; (2) allowing on-going relationships in normalized settings; (3) operating in conjunction with case management; (4) encouraging volunteer participation, but not relying on those as the only source of the services; and (5) in rural areas, "piggy-backing" respite onto existing generic services. Program management and administration issues, such as advisory boards, employee status and opportunity, costs, and evaluation are also reviewed. The final section of the article assesses advocacy and funding developments since the 1970's. This article summarizes information contained in greater depth in the authors' book, *Respite Care: Principles, Programs, and Policies* (listed in this bibliography under Cohen and Warren).

Wikler, L.M., Hanusa, D., Stoycheff, J. (1986) Home-based respite care, the child with developmental disabilities, and family stress: Some theoretical and practical aspects of process evaluation. In Salisbury, C. and Intagliata, J. (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and Their Families* (p. 243-261). Baltimore: Paul H. Brookes.

Key words: stress, rationale, family, program

The authors note that one of the primary goals of respite care is the reduction of stress in families of children with handicaps. According to the authors' summary,

> This chapter summarizes some of the literature on family stress, indicates ways in which respite care may function to affect those stresses, and illustrates these topics by describing the evaluative process of two prevention-oriented respite care projects conducted by the authors (p. 243).

The stresses frequently experienced by parents of a child with disabilities are described. These include persistent, physically exhausting tasks (managing a child with hyperactive behavior, for example); the psychological burdens of the child's dependency needs being prolonged far beyond those of other children; continuous care, with few breaks; and, in many cases, increased social isolation. The authors note that respite care has emerged as a response to assisting these families in the care of their children with handicaps. They also discuss various forms of respite care services.

Wikler, et. al. carried out two projects designed to evaluate the effects of respite services on families. Both studies used trained college students as respite providers. The children served had developmental disabilities and ranged in age from two to twenty. Among other goals met, each project achieved a reduction in the families' burdens of care and levels of stress. Families expressed satisfaction and relief at having a consistent, trained, and reliable person to share the responsibilities of child care. In many cases reduction of stress was accompanied by an increase in social relations. Improvements in some parents' perceptions of the child with disabilities were also noted. According to the authors, respite care served to buffer the cumulative effects of many of the stresses related directly and indirectly to the child's handicap. They assert that respite care can and should serve as a preventive service.

The authors noted that a significant finding in both projects was a hesitancy on the part of parents to use respite services. Often the parents found it difficult to openly express their need to "take a break". "It was as though a 'good' mother should never complain about her own exhaustion or frustrations." (p. 250). There was also a feeling among project participants that good parents concerned themselves first with the needs of others. The authors point out problems with this "myth" (p. 254): first, a parent may not be able to monitor his or her own exhaustion level and so may suddenly find that he or she is emotionally depleted; second, a parent may feel that he or she is being judged as inadequate as a parent by requesting respite services.

The chapter concludes with recommendations for further research and development of respite services. In particular, they call for flexibility in meeting family needs. The authors summarize as follows:

> The goals of respite are: (1) to provide refreshing, energizing breaks that will increase the family's ability to carry out home care while decreasing the emotional costs to its members; (2) to maintain the optimism and loving that the family member as caregiver can best provide; and (3) to avoid burnout that might precipitate neglect, major family disruptions, or placement. Yet, each mother has a unique constellation of personality features, support networks, additional responsibilities, caregiving histories, and social class and ethnic background that will affect her choice of respite care, as well as her satisfaction with it. These differences should be incorporated into evaluations of respite care services (p. 258).

Wilson, P.A. (1986). Informal care and social support: An agenda for the future. *British Journal of Social Work*, 16(supplement), 173-179.

Key word: policy

This article was written following an international conference on the integration of informal helping networks into social work practice. Though not specifically addressing respite service, the article is included because of the relationship of informal support systems and respite care. (See Bamford). The author discusses the rediscovery by social work professionals of informal helping networks, noting that these networks are critical and pervasive in social life. He cautions against treating informal care as a panacea and argues for a disciplined, precise, and differentiated set of professional interventions based on patterns of informal care. These should be determined by various client-related situations and circumstances. The author emphasizes the need to: (1) disentangle informal caring from other social work issues, (2) define rigorously the forms of informal caring, and (3) make available resources for the development and integration of formal and informal helping systems.

SOURCES OF RESPITE INFORMATION OR SERVICES

Alleghany County Mental Health Department
Wood Street Commons
304 Wood Street
Pittsburgh, PA 15222
(412) 355-7118
Georgianno Palaoro

Association for Retarded Citizens
314 West Bute Street
Norfolk, VA 23510
(804) 623-1131
Ellen Seal

Association for the Care of Children's Health
Family Centered Care Project
3615 Wisconsin Avenue, NW
Washington, D.C. 20016
(617) 251-7075
Ibby Jeppson/Terry Shelton

Atlanta Respite/Day Care Center, Inc.
Georgia-Hill Neighborhood Facility
Suite 304
250 Georgia Avenue, SE
Atlanta, GA 30312
(404) 658-1090
Gwendolyn G. Conley

Autism Services Association, Inc.
99 School Street
Weston, MA 02193
(617) 891-9386
Barbara Cutler

Center for Children and Parents
3745 Community Park Loop
Suite 102
Anchorage, AK 99508-3466
(907) 276-4994
Karen Johnson

Community Association for Retarded, Inc.
Jane Mallen Respite House
3864 Middlefield Road
Palo Alto, CA 94303
(415) 494-0550
William Murray

Coordinating Council for Handicapped Children
20 East Jackson
Room 900
Chicago, IL 60604
(312) 939-3513

Crisis Parent Program
Child Protective Services Unit
Fairfax County Dept. of Social Services
10301 Democracy Lane
Fairfax, VA 22030
(703) 246-5700
Kevin Filby

Easter Seal Society of Iowa
P.O. Box 4002
Des Moines, IA 50333
(515) 289-1933
Jack Denniston

Easter Seal Society of Virginia, Inc.
Time Out for Parents Respite Care Program
P.O. Box 5496
Roanoke, VA 24012
(703) 669-5433

Eastern Nebraska Community Office of Retardation
Family & Medical Support Services
885 South 72nd Street
Omaha, NE 68114
(402) 444-6108
ENCOR Intake Advisor

Family Support and Resource Center
521 North Sherman Avenue
Madison, WI 53704
(608) 246-0414
Heidi Rossiter

Family Support Center
2020 Lake Street
Salt Lake City, Utah 84105
(801) 487-7778
Marty Shannon

Family Support Program
Developmental Disabilities Office
1 West Wilson, #433
Madison, WI 53707
(608) 266-7469
Beverly Doherty

Gloucester Dept. of Social Services
P.O. Box 1390
Gloucester, VA 23061-0186
(804) 693-2671
Linda Miller

Hogg Foundation for Mental Health
P.O. Box 7998
University of Texas Station
Austin, TX 78712
(512) 471-5041
Ralph Cruller

James City County
Dept. of Social Services
P.O. Box 69
Lightfoot, VA 23090-0069
(804) 565-6855
Diana Hybicki

Judevine Center for Autistic Children
9455 Rott Road
St. Louis, MO 63127
(314) 849-4440
Daniel Jackson

Kansas Families Together, Inc.
P.O. Box 86153
Topeka, KS 66686
(913) 273-6343
Richard Donner

Kentucky Division of Mental Health
Children's Branch
275 E. Main Street
Frankfort, KY 40621
(502) 564-7610
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Lane County Association for Retarded Citizens
P.O. Box 5543
2025 Washington St.
Eugene, OR 97405
(503) 343-5256
Pam Ring

Maine Respite Project
159 Hogan Road
Bangor, ME 04401
(207) 941-4400
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Mount Tom Institute for Human Services
507 Appleton Street
Holyoke, MA 01040
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National Information Center for Children and Youth with Handicaps
7926 Jones Branch Drive
Suite 1100
McLean, VA 22102
(703) 893-6061
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New Orleans YWCA
1833 Louisiana Avenue
New Orleans, LA 70115
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2115 East Cedar Avenue
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Oklahoma Department of Mental Health
c/o Oklahoma Youth Center
1200 East Main Street
P.O. Box 1008
Norman, OK 73070
(405) 364-9004
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Parent Services Project
Fairfax-San Anselmo Children's Center
199 Porteous Avenue
Fairfax, CA 94930
(415) 454-1811
Ethel Seiderman

Parent's Relief Nursery
P.O. Box 555
Roseburg, OR 97470
(503) 673-4354
Judy McEver

Parents Information Group
416 West Onondaga Street
Syracuse, NY 13202
(315) 446-3735
Michaeline Bendetti

Project Time-Out
25 Moor Avenue
Mt. Kisco, NY 10549
(914) 666-0908
Elizabeth Stern

R and R Program
1220 South Division
Spokane, WA 99202
(509) 447-3192
Jim Mahoney

Respite Care Association of Wisconsin
1675 Dousman
Green Bay, WI 54301-0565
(414) 498-2799
Jan Lapacz

Respite Care Training Program for Rural Areas
The Early Intervention Research Institute
Utah State University
UMC 6580
Logan, UT 84332
(801) 752-2000
Glendon Casto

Texas Respite Resource Network
Children's Ambulatory Care Center
P.O. Box 7330, Station A
San Antonio, TX 78285
(512) 228-2794
Liz Newhouse

Tri-County Respite Care
P.O. Box 5778
4450 SW 184th
Aloha, OR 97006
(503) 642-1721 or 222-7314
Cheryl Connell

United Cerebral Palsy of Northeastern Maine, Inc.
Respitality Program
103 Texas Avenue
Bangor, Maine 04401
(207) 941-2885
Priscilla Haley

University of Missouri-Kansas City
Institute for Human Development
2220 Holmes Street
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Kansas City, MO 64108-2676
(816) 276-1770
Carl F. Calkins

Volunteer Emergency Foster Care of Virginia, Inc.
2317 Westwood Avenue
Suite 109
Richmond, VA 23230
(804) 353-4698
William Christian

Washoe County Dept. of Human Services
Washoe County Respite Care Project
P.O. Box 6274
Reno, NV 89513
(702) 323-4533

Westchester Self-Help Clearinghouse
Westchester Community College
Academic/Arts Building
75 Grasslands Road
Valhalla, NY 10595
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